



The Parkinsonism Society of New Zealand (Inc)

Parkinson's New Zealand is a not for profit organisation that offers support, education and information to people living with Parkinsonism conditions, their families, carers and health professionals. Parkinson's New Zealand has divisions and support groups nationwide.

We can offer:

- ✦ Information on Parkinson's and Parkinsonism conditions including PSP
- ✦ Regular up-to-date information through our national magazine, website and local newsletters
- ✦ Responsible reporting of recent research
- ✦ Books and audio-visual material
- ✦ Local meetings and education programmes
- ✦ Advice on health and welfare assistance available
- ✦ Support from a professional Field Officer in your area
- ✦ Fellowship and support



Parkinson's New Zealand is reliant on funding from grants, bequests and donations. Your support is welcome!

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Your local contact is:

February 2008 - Designed by Gibson Rusden

An introduction to Progressive Supranuclear Palsy (PSP)

www.parkinsons.org.nz



Progressive Supranuclear Palsy (PSP)

What is PSP?

PSP is a rare degenerative neurological condition often presenting with similar symptoms to Parkinson's disease.

The condition begins slowly and continues to get worse (progressive), causes weakness (palsy) by damaging certain parts of the brain above pea-sized structures called nuclei that control eye movements (supranuclear).

What causes PSP?

The cause of PSP is not known. Scientists have come up with several theories as to why the brain would degenerate in such a way. PSP could result from exposure to a virus that enters the body and then takes years to produce obvious effects or be the result of complex genetic mutations. None of these theories have been proven.

Who gets PSP?

Middle aged to elderly adults – in New Zealand roughly 6 in 100,000 people over the age of 60. This figure may rise as more doctors become familiar with the clinical signs and diagnosis is more accurate. It is thought that the disease has a long incubation time without symptoms. It can be years before signs are evident. The disease is not inherited or contagious.

Symptoms of PSP?

The key clinical signs of PSP can include :

- ✿ Unsteady walking and frequent unexplained falls, mainly backward
- ✿ Stiffness of the neck and limbs
- ✿ Visual problems – an inability or reduced ability to look up or down, light sensitivity, slow blinking of eyelids and difficulty maintaining eye contact
- ✿ Slow, slurred quiet speech
- ✿ Difficulty swallowing
- ✿ Slowness of movements generally.

Mental Health

Studies have not been done that can tell us how often mental health problems occur in PSP but they are probably relatively common at some point in the illness. A person with PSP may experience depression and/or anxiety. Some people may experience heightened emotions. Hallucinations and a loss of motivation may develop. Additionally, adjusting to the presence of various symptoms or losses of independence is very challenging and people will benefit from support when it is hard to cope.

How is PSP diagnosed?

The diagnosis may be difficult. PSP is often mistaken for Parkinson's, Alzheimer's or depression especially in the early stages of the condition. An assessment by a specialist is essential to determine the diagnosis. There is no specific diagnostic test for PSP. A period of observation is often needed before the diagnosis can be made.

What is the prognosis?

PSP is a progressive disorder. People with PSP have an increased risk of complications such as pneumonia and inability to swallow. It is not possible to accurately predict the life expectancy of a person with PSP because there is so much variation. This is for a number of reasons including the age of the person. However, the average life expectancy after diagnosis was between 7 and 9 years in studies that have looked at groups of people with PSP.

What is the treatment?

Some people with PSP present with Parkinson's symptoms including asymmetry and tremor. A proportion of people respond moderately to treatment with Levodopa (Madopar/Sinemet). A variety of medications and other forms of therapy can help control the symptoms. There are no specific treatments for PSP.

People with PSP may benefit from working with a multi disciplinary team that could include Physiotherapists, Speech Therapists, Dieticians, Occupational Therapists and Parkinson's New Zealand Field Officers.

To the person with PSP and their family

The diagnosis of PSP has significant impact on those close to the person with PSP. Progressive disability results in an increasing need for care and support. Carers and families may feel isolated, frustrated and chronically tired. Support services can be contacted directly or referral can be made through your doctor, other health professional or Parkinson's New Zealand Field Officer.

PSP Support Network

An informal PSP Support Network for people with PSP and their families is co-ordinated by Sue Lacy. The support network offers resource information and telephone enquiries to help network people with PSP, carers and families.

Contact: Sue Lacy
Phone: 06 345 2211
Email: sue.lacy@clear.net.nz.

Further resources on the Internet

There is a lot of information about PSP available on the Internet; the following sites may be of interest:

www.neurosy.org/disease/psp/psp-answers
www.neurosy.org/disease/psp/stages
www.neurosy.org/disease/psp/challenges
www.neurological.org.nz

